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= **AWARENESS**

## Colorado Gives Day is on Tuesday, December 6

**Colorado Gives Day** is an annual statewide movement to celebrate philanthropy in Colorado through online giving. Our goal is to raise \$10,000 this year on December 6. Why? "Because every year I see new people come to our Foundation dealing with this incredibly difficult disease, but I know there are more in the Rocky Mountain region who are not getting the support they need and think they are alone. I'm spurred to generate more out reach in the coming year so that everyone with scleroderma knows we are here to provide support, education and information, or just lend a friendly ear to get them through a tough day," says Cyndy Besselievre, Executive Director. You can pre-schedule your donation today at [www.coloradogives.org/rockymntscleroderma](http://www.coloradogives.org/rockymntscleroderma).

## "Virtual" Support Group on November 10

How do you boost your immune system to help stay healthy while taking immunosuppressant medications? That's just what **Shelley Van Pelt, RN, MSN, CNS** will discuss on **Thursday, November 10 from 7:00-8:00 pm** when she joins us to host our "virtual" support group teleconference with "Building Your Immunity With an Autoimmune Disease".



To participate in the teleconference, call **(712) 775-7031** and enter code **781-611-035#** when prompted. Time will be allowed for your questions.

## Patient Education Day Videos

If you missed our recent Patient Education Day, or if you would like to see any of the presentations again, you are in luck! Thanks to Jerry Brown PR, all the sessions were recorded and are now available at [www.youtube.com/COScleroderma](http://www.youtube.com/COScleroderma).

## New Scleroderma Support Group in Rio Rancho

Anna Wenger was diagnosed with scleroderma in 2004 at just 12 years old. At age 22 she was told she has PAH and ILD. But Anna does not let it get her down; instead she wants to help others. That's why she is starting a support group in Rio Rancho, NM. The **Albuquerque/Rio Rancho support group** will hold its first meeting on **Saturday, Nov. 12 from 1:00-3:00 pm** at the **Sabana Grande Recreation Center**, 4110 Sabana Grande Ave. SE, Rio Rancho, NM 87124. For more information, contact Anna at 505-974-9293 or [annawenger91@gmail.com](mailto:annawenger91@gmail.com). "My goal is



to have a safe place to go for support for anyone impacted by scleroderma, to help people feel empowered despite their disabilities and to help spread awareness," says Anna.

## What's Happening

- **Nov. 10, 2016** – Virtual support group teleconference with Shelley Van Pelt.
- **Nov. 29, 2016** – Holiday Shopping for Scleroderma at Carla's A Classic Design in The Streets at Southglenn. (See p. 4)
- **Dec. 6, 2016** – Colorado Gives Day

For more information, go to [www.scleroderma.org/colorado](http://www.scleroderma.org/colorado) or contact us at **(303) 806-6686** or [cochapter@scleroderma.org](mailto:cochapter@scleroderma.org).



The American Dental Association hosted its 2016 National Convention in Denver from Oct. 20-22 at the Colorado Convention Center. We were there with a booth and educated hundreds of dentists, hygienists and students about scleroderma and the related dental implications.

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## Chapter Board Update

Fall has finally arrived here in Colorado and I am witnessing vibrant colorful changing of the leaves. I am grateful for fall as it reminds us to be open to change and transformations. On this note, our Chapter continues to transform and grow.

As we reflect on accomplishments and failures, we as a Board revisited our staffing and volunteer needs and established new goals for 2017. This led us to think about one of our biggest successes which was the addition of the "Food Fight!" to our fundraising events. This was achieved with the help of Alison Oyler-Mitsch and the staff of Fresh Events.

As we look to our Stepping Out Walks, we have the same thought, could an event planner be the answer? We are not certain, but we are reallocating the funds we set aside for a Chapter Manager and are going to rethink what we need to be successful. More to come on this in the coming months.

We are very focused on our Walks, not only how to grow them but how to make them more engaging, creative and fun. Our Walks are a time for camaraderie and friendship but they are also a great time to create awareness for scleroderma. With

this in mind, we are seeking ways to host some awareness events in the month of June with the help of our Walk team captains, along with new challenges before and during the Walks to give teams more incentive to raise awareness.

Lastly, we also have spent much time on outreach in our community. How do we reach more patients? How do we grow volunteers? How do we engage the young to help drive our mission? We are working on some awareness opportunities and still seek volunteers to help with our events. We keep streamlining our needs so volunteers will not be overwhelmed with work, but can engage in kinship and activities that really help us to organize these events in a simple way.

Yes, we need your help! My ask is that you share your ideas; ask a friend to help with our events and join us to educate; get social - like, share, comment on our posts; support one another; and raise funds for research by increasing awareness in a fun and creative way. Call or email me, I'd love to meet you with you and hear your ideas ([trice@scleroderma.org/303-478-6642](mailto:trice@scleroderma.org/303-478-6642))

In Thanksgiving,  
Theresa Rice, Chapter President

## Support Group News

Support groups offer a friendly forum to meet others in your area living with scleroderma. Patients, caregivers, family and friends are all welcome. For more information, visit our website at <http://bit.ly/COSupport>.

### **"VIRTUAL" SUPPORT GROUP TELECONFERENCES**

November 10, 2016 – Shelley Van Pelt, RN, MSN, CNS will discuss "Building Your Immunity With an Autoimmune Disease".

February 9, 2017 – Speaker and topic to be announced.

**Teleconference calls are from 7:00-8:00 pm. To participate call (712) 775-7031, enter code 781-611-035# when prompted.**

### **MILE HIGH (DENVER) SUPPORT GROUP**

November 12, 2016 – Amy Johnson will share her story about living with scleroderma and a recent stem cell transplant.

December 10, 2016 – Holiday party!

January 14, 2017 – To be announced.

February 11, 2017 – To be announced.

March 11, 2017 – To be announced.

**Meetings are from 11:00 am-1:00 pm at the Arthritis Foundation, 2280 S. Albion St., Denver, CO 80222.**

### **SOUTHERN COLORADO SUPPORT GROUP**

November 19, 2016 – Holiday luncheon at 11:30 am at the Edelweiss Restaurant, 34 E. Ramona Ave., Colorado Springs, CO 80905. **(NOTE: Different time and location for this event.)**

January 21, 2017 – To be announced.

March 18, 2017 – Sandee Billen Maas will present on the Basics of Essential Oils.

**Meetings are from 11:00 am-1:00 pm at Penrose Cancer Center, Room CC-A, 2222 N. Nevada Ave., Colo. Springs, CO 80907.**

### **NORTHERN COLORADO SUPPORT GROUP**

December 3, 2016 – Holiday luncheon at 11:00 am at The Moot House, 2626 S. College Ave., Fort Collins, CO 80525. **(NOTE: Different date, time and location for this event.)**

February 25, 2017 – Julie Knighton, RN, MSN, Community Health Education Coordinator, will discuss programs available through UCHealth related to living with chronic conditions and pain. **(NOTE: This meeting to held in the Big Thompson Canyon Room.)**

**Meetings are from 10:00 am – 12:00 pm at the Medical Center of the Rockies, Mt. Meeker and Arapahoe Peaks Rooms (lower level), 2500 Rocky Mountain Ave., Loveland, CO 80538.**

### **WESTERN SLOPE (GRAND JUNCTION) SUPPORT GROUP**

November 12, 2016 – Holiday party and update on workshops presented at the 2016 National Patient Education Conference.

January 14, 2017 – To be announced.

March 11, 2017 – To be announced.

**Meetings are from 11:00 am – 1:00 pm at Community Hospital, Legacy 1 Room, 2351 G Road, Grand Junction, CO 81505.**

## ***Sometimes Autoimmune Diseases “Buddy Up” – Bobbie Jo Knows This All Too Well – Here is Her Story***

Bobbie Jo Sanchez was born and raised in Anthony, NM where she graduated from Gadsden High School. She received an associate degree in nursing from Roswell Eastern New Mexico University. Bobbie Jo married and raised a son Jeremy and a daughter Santana in Anthony in a house she built on land passed down from her grandfather. (Her father worked in the school system and collected old playground equipment. Bobbie Jo’s daughter and now her son’s three daughters enjoy playing on it in their own back yard!)

Bobbie Jo worked as a nurse for 35 years. She worked in a variety of settings including a hospital, clinic, nursing home, home help and case management for the disabled, elderly and pre-natal. In 2006, she started a personal care option company but had to stop working in 2008 when she got too sick. Bobbie Jo loved her job so this was a difficult decision.

Bobbie Jo was diagnosed with mixed connective tissue disease in 1982 because she initially had symptoms of multiple immune disorders. This diagnosis was quickly followed by lupus. The weather in Anthony is dry and hot. This often affected Bobbie Jo’s eyes causing scarring of the cornea and ulcers in her eyes, as well as bronchitis. This ultimately led to a diagnosis of Sjogren’s Syndrome. It was also about this time that Bobbie Jo’s hands started turning cold and blue. She also developed leg pain and a limp. Her doctors told her to get ANA testing but she otherwise felt that they never really listened to all her symptoms, even knowing that she was a health professional herself. She feels her medical background gave her the knowledge to question what her doctors told her. She felt the rural doctors mostly treat the basic needs and don’t have the experience to address more complicated diseases like hers.

Bobbie Jo went blind after her son was born, which was attributed to her multiple mixed connective tissue disorders. It was a very scary 3 weeks until her vision returned because no one could tell her if she would ever see again.

Bobbie Jo was put on massive doses of Prednisone which she took for almost 30 years. She was kept on Prednisone while pregnant with Santana but it was considered a high-risk pregnancy. A month before her due date, while at a regular check up, her doctor sent Bobbie Jo to the hospital to induce labor because her embryonic fluid was too low (probably related to the lupus). With all of Bobbie Jo’s conditions, Santana was tested before she even left the hospital and fortunately had no markers for autoimmune diseases. The long term treatment on Prednisone has caused osteoporosis and Bobbie Jo has had many bone fractures as a result. She was finally weaned off Prednisone in 2013 and now takes it just as needed. She tried Cytoxan but did not tolerate it well.

In 2004, Bobbie Jo caught pneumonia and was in and out of the hospital. She passed out several times. A local pulmonologist put her on Flolan but used the PICC line for other medications too which almost killed her. Her cardiologist got her out of the hospital and on a plane to

Denver to the University of Colorado Hospital. Bobbie Jo was so sick she doesn’t even remember her first week here. While at the hospital, she was treated by Dr. Todd Bull who diagnosed her with pulmonary arterial hypertension (PAH). She was weaned off Flolan after 2 years and now takes Tracleer, a diuretic and blood pressure medication for PAH. When she started on Tracleer, she was also in a research study for Tadalafil (better known as Viagra!).



*Santana and Bobbie Jo at the 2015 National Patient Education Conference*

It was at this time that Bobbie Jo was first seen by Dr. Aryeh Fischer and finally diagnosed with scleroderma. In 2011, she was diagnosed with vocal cord paralysis that she attributes to her Sjogren’s Syndrome. She also has esophageal strictures. She has had her throat stretched and went to speech therapy but has seen no real improvement. She also has gastrointestinal problems related to scleroderma. She has been diagnosed with dumping syndrome, irritable bowel syndrome and GERD.

Bobbie Jo waited to move to Colorado until after Santana graduated from high school. It was her great fortune that Santana was going to attend CO School of Mines in Golden so Bobbie Jo could be closer to her doctors and Santana.

Bobbie Jo is doing better but still has bad days. She still gets pneumonia but recovers. She is developing calcinosis in her fingers, lungs, jaw, liver and on her back. The calcinosis blocks her glands which causes swelling. When it gets too bad, she is treated with antibiotics to reduce the swelling.

She is in need of a double lung transplant but is not eligible due to her many autoimmune disorders. She also has a torn rotator cuff and torn meniscus that will never get repaired because she is too at-risk for any surgery unless it is an emergency. But Bobbie Jo looks on the brighter side – at least she’ll never have to have a colonoscopy!

Bobbie Jo has always known that someone with one autoimmune disease often develops others and she is proof of that! Her doctors have told her she has the lives of a cat; but mostly it is her strong faith that keeps her going.

Bobbie Jo loves music, cooking and baking. She took up quilting two years ago and also enjoys walks, movies and taking line dancing classes. She volunteers at the Scleroderma Foundation because she believes in its mission, as well as at her church (where she is a Eucharistic minister) and other autoimmune organizations.

Bobbie Jo is fluent in Spanish. She wants to do more with the Scleroderma Foundation to spread awareness in the Spanish speaking community and help those not fluent in English better understand the medical terminology and living with scleroderma. You can help Bobbie Jo realize her dream by supporting the Scleroderma Foundation on Colorado Gives Day.



## ROCKY MOUNTAIN CHAPTER

2280 S. Albion St. · Denver, CO 80222

*The Scleroderma Foundation-Rocky Mountain Chapter thanks **Rising Graphics + Printing of Evergreen** for their assistance with producing our quarterly newsletter.*

### **Holiday Shopping for Scleroderma! Carla's A Classic Design**

Please join us for a night of shopping, refreshments and fun!

**Tuesday, November 29<sup>th</sup> 4:00 – 8:00 pm**

Come in & let Carla's help you with your holiday gift list!

Carla's has everything from unique gifts for teachers, mailmen and neighbors to loved ones & everything for the home.

Carla's also gift wraps and ships!

**10% of all sales will go to the  
Scleroderma Foundation-Rocky Mountain Chapter**



Carla's A Classic Design  
The Streets at Southglenn  
6851 S. Gaylord St., #233  
Centennial, CO 80122  
303-683-0372



Please RSVP by 11/21/16 to Michelle  
[michelle@carlasacd.com](mailto:michelle@carlasacd.com) or 303-683-0372

### **How To Donate**

1. Please remember us when you support your favorite Colorado charities on Colorado Gives Day, Tuesday, December 6 at [www.coloradogives.org](http://www.coloradogives.org).
1. Mail your check payable to the Scleroderma Foundation-Rocky Mountain Chapter to 2280 S. Albion St., Denver, CO 80222.
2. Donate securely and safely on-line at [www.scleroderma.org/colorado](http://www.scleroderma.org/colorado).
3. Check with your employer about payroll deductions for donations (and ask them about their matching programs).
4. Create a legacy by planned giving or remembering us in your will. Get started at [sclerodermafoundation.myplannedgift.org](http://sclerodermafoundation.myplannedgift.org).



### **Contact Us At...**

Scleroderma Foundation  
Rocky Mountain Chapter  
2280 South Albion St.  
Denver, CO 80222  
(303) 806-6686  
[cochapter@scleroderma.org](mailto:cochapter@scleroderma.org)

### **Follow Us At...**

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[www.youtube.com/COScleroderma](http://www.youtube.com/COScleroderma)

### **Meet Others At...**

[www.inspire.com/groups/scleroderma-foundation](http://www.inspire.com/groups/scleroderma-foundation)

**“DON'T LET YESTERDAY  
USE UP TOO MUCH  
OF TODAY.”**

*Will Rogers*